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Care of the Asian American Child With Cleft Lip or Palate

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Orofacial clefts are one of the most common global birth defects. Orofacial clefts may be part of a syndrome or an isolated birth defect, and affect approximately 1–1.5 per 1,000 live births worldwide with noted inequalities across geographical areas and cultures. In the United States, Asian American populations have a substantially higher incidence of cleft lip with or without cleft palate (2/1,000 live births). Orofacial clefts are a key health issue with substantial health care costs, and associated medical, psychological, and social ramifications. It has been estimated that the health care costs within the United States are approximately $697 million over a child's lifetime. In disorders like orofacial clefts, because of the complexity of the condition and subsequent medical interventions, as well as the cultural intricacies of the Asian culture, it requires significant knowledge and understanding by the health care providers. In order to provide optimal and safe cleft care, reduce health care costs, and improve the outcomes for the Asian American population, a culturally sensitive, multidisciplinary, and coordinated approach is needed. Increased culturally specific education, early access to prenatal care, and ongoing infant and pediatric health care are essential.

Orofacial clefts are a category of one of the most common birth defects, and include the craniofacial anomalies of isolated cleft lip or cleft palate, or a combination of both (Mancuso, 2015, para 1). Clefts develop early in pregnancy, and although the cause is unknown, there are genetic and environmental factors that have been shown to contribute to the development of orofacial clefts. In the United States, the incidence of cleft lip and/or cleft palate has been shown to occur the most frequently in the Asian American (1/700 live births) (Dixon, Marazita, Beaty, & Murray, 2011; Mossey, Little, Munger, Dixon, & Shaw, 2009). Care of the Asian American cleft child is complex and associated with substantial health care costs. Multidisciplinary team members need to consider cultural values of this population when making health care decisions in order to improve access and early intervention. This article reviews cleft lip and cleft palate, including risk factors, incidence, associated complications, and treatments. In addition, a brief overview of the Asian American health beliefs, culture values, and social issues has been discussed within the context of the child with a cleft lip and/or palate.

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DEFINITION AND EPIDEMIOLOGY OF CLEFT LIP AND CLEFT PALATE

In normal growth and development in utero, the fetus's roof of the mouth (palate) and upper lip are formed when tissues and bones of the mouth, nose, and upper jaw fuse or come together. Orofacial clefts occur in utero between weeks 6 and 11 of the pregnancy when these structures do not close or fuse completely (American Academy of Otolaryngology [AAO], 2017; Kosowski, Weathers, Wolfswinkel, & Ridgway, 2012).

A cleft lip is an opening or a split (cleft) in the upper lip and can be unilateral or bilateral. Openings can be quite small, and sometimes may only look like a small notch. This is known as an incomplete or partial cleft lip. A complete cleft lip is when the cleft goes through the lip, upper gum line, palate, and into the base of the nose (Kosowski et al., 2012). A cleft palate has occurred when there is an opening in the roof of the mouth. A cleft of the palate can be an isolated cleft or associated with a cleft lip. It is not uncommon to see the uvula split with a cleft palate. A cleft of the palate can also be of varying sizes, and can be a hole of the soft palate near the back of the roof of the mouth (which contains no bone), or near the front of the mouth in the hard palate. A cleft of the soft palate is also called a submucous cleft palate, and this cleft oftentimes is not noted until after birth. When a cleft also involves the gum tissue (cleft alveolus), there is a breach in the bone that goes from the base of the nose to the front teeth, creating an opening between the nose and the mouth (Kosowski et al., 2012).

Etiology and Risk Factors

The etiology of orofacial clefts is unknown, and they are not preventable. However, environment and genetics

have been shown to play a role (AAO, 2017; Allam, Windsor, & Stone, 2014; Dixon et al., 2011; Kosowski et al., 2012). Many children have cleft lip and/or cleft palate as an element or component of a syndrome, and it has been associated with other developmental abnormalities and inherited diseases as well. There are approximately 400 plus syndromes that cleft lip and/or cleft palate are associated with. Some of the more common syndromes include Waardenburg syndrome, DiGeorge syndrome, Van der Woude syndrome, Pierre Robin sequence, velocardiofacial syndrome, hemifacial microsomia/Goldenhar syndrome, Tessier facial clefts, and Down syndrome (AAO, 2017; Burg, Chai, Yao, Magee, & Figueiredo, 2016).

Genetically, it has been shown there is a familial tendency in all clefts, and clefting can be passed on through many generations (Allam et al., 2014). A mother and/or father, or both, can pass on the gene that causes cleft lip and/or cleft palate. The risk of a fetus developing a cleft lip and/or palate increases significantly if both parents have a cleft. According to the Cleft Lip & Palate Association [CLAPA] (2019), if only a single parent has a cleft, there is an approximate 5% chance a baby will be born with an inherited cleft, although if both parents have no history of cleft, but give birth to a baby with a cleft, there is a 2%–4% chance that a second child will be born with a cleft as well. There are several other factors that have also been identified that increase the risk of fetus developing an orofacial cleft.

Environmental risk factors have been identified in the literature that are thought to contribute and increase the risk of the development of an orofacial cleft in a fetus with an inherited cleft lip and/or palate gene. According to the Centers for Disease Control and Prevention [CDC] (2017), exposure and indulging in cigarette smoking, as well as consumption of alcohol or drugs during pregnancy, increases the probability and risk of having a baby with a birth defect such as an orofacial cleft. Margulis et al. (2012) and Werler et al. (2011) found that women who take antiseizure medications such topiramate (Topamax) or valproic acid (Depakote/Depakene) during the first 3 months of pregnancy have an increased risk of having a baby with a cleft versus women who do not take these medications. Similarly, Burg et al. (2016) and Molina-Solana, Yanez-Vico, Iglesias-Linares, Mendoza-Mendoza, and Solano-Reina (2013) found that women with a low intake of folic acid, and deficiencies in other prenatal nutrients needed during pregnancy such as zinc, are at increased risk. Examples of other medications that have been associated with increased risks for clefts include a medication used to treat acne (Accutane), and methotrexate, a medication that is utilized to treat cancer, psoriasis, and arthritis (Kummet et al., 2016). Other maternal risk factors associated with clefts include maternal obesity, diabetes, maternal older age, and exposure during pregnancy to certain infections such as rubella (CLAPA, 2019; Molina-Solana et al., 2013).

Incidence and Populations at Risk

Studies have shown that the national incidence of babies born with orofacial clefts with both cleft lip and cleft palate are approximately 1–1.5 per 1,000 live births (AAO, 2017; Tanaka, Mahabir, Jupiter, & Mendez, 2012). When looking at incidence related to gender, males are two times more likely to have a cleft lip and/or palate, whereas females more commonly have an isolated cleft palate (CDC, 2017; Martelli et al., 2012). According to the National Institute of Dental and Craniofacial Research [NIDCR] (2014), and the CDC (2017), it was estimated that in the United States, from 2004 to 2006, there was an average prevalence of isolated cleft palate in 6.35 per 10,000 live births (2,650 cases), and a prevalence of cleft lip with or without cleft palate of 10.63 per 10,000 live births (4,440 cases). The CDC and the NIDCR gave further statistics that one out of every 1,570 infants is born with isolated cleft palate, and 1 out of 940 babies is born with an isolated cleft lip or with a cleft palate in the United States alone. One more recent international study demonstrated that globally, in the years 2000–2005, there was an overall incidence of cleft lip in 9.92 per 10,000 live births, isolated cleft lip in 3.28 per 10,000 live births, and in combined cleft lip and palate, there was an incidence of 6.64 per 10,000 live births (Mastroiacova, 2011, para 1). The unilateral left cleft lip occurs more frequently than the right or bilaterally (Mancuso, 2015, para 5). The estimated health care costs are approximately $697 million over a lifetime to treat the children who are born with orofacial clefts every year in the United States (NIDCR, 2014).

One of the largest research studies to date examined birth defects, and the ethnic and racial differences in the United States from 1997 to 2007. Data were obtained from a 12 state-based tracking system for birth defects (CDC, 2017). In this study, Canfield et al. (2014) found that, when comparing non-Hispanic Whites to other ethnicities, the Native American and Asian American populations had a substantially higher incidence of cleft lip with or without cleft palate (2/1,000 live births). The African American population had the lowest incidence (1/2,500 live births). The Asian American population is growing rapidly in the United States, and they currently are approximately 4% of the current population (United States Census Bureau [USCB], (n.d.). According to the USCB, the Asian American population is projected to increase to approximately 38 million (9.3% growth) by the year 2050, which may result in a significantly higher incidence of this condition.

ASIAN AMERICAN CULTURE AND HEALTH BELIEFS

The Asian American is a very diverse ethnic group and with many differences in language and cultural beliefs among themselves. However, Asian Americans have a strong sense of family, family values, and personal relationships.

Their extended family and older family members carry a significant influence over the rest of the family. In many families, the oldest male will be the spokesman and decision-maker for the family (McLaughlin & Braun, 1998). Because of the beliefs and values in tradition and folk medicine, Asian Americans will often pursue health care within their own ethnic group first before pursuing Western medicine (Cheng, 1990). In the Asian American culture, harmony is valued, authority is respected, and conflict and confrontation are avoided. Consequentially, Asian Americans often will not disagree with a health care provider's recommendations, but this does not mean they agree with the health care recommendations of treatment (Cheng, 1990).

According to the Asian & Pacific Islander American Health Forum [APIAHF] (2011), socioeconomic status is a barrier for many Asian Americans in obtaining and utilization of health insurance or finding work that offers a health insurance plan (APIAHF, para 5). According to the APIAHF, there are several million Asian Americans who have limited insurance, or who have had no insurance at one time in the previous year. The APIAHF also provided statistics that among "Asian Americans, there is approximately 55% of Korean Americans who are likely to be uninsured; other uninsured groups include Vietnamese (37%), Asian Indians (18%), Chinese (16%), Filipinos (15%), and Japanese (4%)" (APIAHF, para 2).

In addition to a lack of health insurance, their language barriers, as well as their cultural barriers, influence access to health care for the Asian American population. Contributing factors include the Asian American's outlook on disabilities, disease, and illness, which is quite different from the overall population. Many of those who do not speak or understand the English language well will not access or seek medical care because of a lack of understanding and difficulty in navigating the health care system, and the difficulty in communicating with providers (APIAHF, 2011, para 5). The provision of health care for the Asian American with a birth defect such as orofacial clefts can be a challenge because of the cultural differences and beliefs of this population. The overall culture looks at a handicap/birth defect as a result of ancestry wrongdoing, which leads to shame and guilt (Cheng, 1990, p. 296). Food plays a role within their philosophical beliefs as well. An example would be if a woman eats rabbit while pregnant, she will have "hare" lip baby (Cheng, 1990). Others think that certain foods have healing properties. A lack of knowledge about a specific disability or illness can cause a tremendous amount of fear, hostility, alienation, and blame.

Religious and philosophical beliefs vary within the Asian American population. Some look at birth defects as one's fate or bad karma, whereas some have a defeatist and stoical attitude about a handicap and choose to do nothing. Certain subsets of the Asian American population look at clefts or other birth defects in an infant/child as a gift from God, and have to be protected and shielded by all. Others view it as a curse (McLaughlin & Braun, 1998).

There are different beliefs regarding hospitalization as well. Ambulances are associated with taking a person away to die, whereas hospitals are thought of as a threatening institution where one goes only if he or she has a fatal injury or long-lasting incapacitating disease. There are some subcultures within this ethnic group who believe that if people need surgery their spirit leaves them. Others look at therapists as not "important" because they do not cure individuals. This belief presents issues in the care of cleft children who will need speech therapy as they grow and mature (APIAHF, 2011; Cheng, 1990, p. 296). The cultural perspectives, and the related health problems associated with cleft lip and/or palate, challenge providers to acknowledge and consider the cultural diversity of the Asian American with a cleft in order to provide the subsequent medical and surgical interventions needed to treat clefts (Cheng, 1990).

RELATED HEALTH PROBLEMS, SOCIAL ISSUES, AND TREATMENT OF CLEFT LIP AND CLEFT PALATE

The problems and complications that are associated with a cleft will depend on the severity and location of the cleft, and the overall health of the infant/child. For Asian American families with a cleft baby, because of their current beliefs and family-based values, they may first get advice and suggestion from a family member, a folk medicine doctor, or a physician of the same ethnicity before seeking Americanized health care for their child. Seeking Westernized physicians can be considered a last resort for Asian Americans, because of their respect for authority, they are giving up or relinquishing medical decisions to the provider. Their folk beliefs and views can lead to a delay in treatment for these children (Cheng, 1990). Early screening and assessment of the infant/child with an orofacial cleft, by a provider familiar with their culture, is important so as to detect other associated syndromes or conditions, and provide timely management and services.

Airway and breathing can be compromised in these children, subsequently oftentimes requiring the child to wear an oral appliance or undergo surgical intervention. Because of the hole in the roof of the mouth in a cleft palate infant, feeding can be an issue and challenge. When an infant eats and swallows, it is not uncommon to see this food come out through the nose. These children oftentimes have difficulty latching on to the breast or sucking a bottle due to the inability to create a seal because of the cleft in the palate. This results in the infant swallowing air and then regurgitating up through the nose (Goswami, Jangra, & Bhushan, 2016; McLaughlin & Braun, 1998). Asian Americans might not express their concerns to

difficulties with feeding, so it is important that providers speak to this, and assess for weight loss. Providing bottles and nipples that are specially designed for infants with sucking and feeding issues (Haberman or Pigeon nipple) will facilitate normal weight gain in these children.

In normal development, the ear is connected with the mouth. In the cleft palate child, ear infections and hearing loss are common because of the structures affected. Because of these changes, many of the kids with cleft palate have Eustachian tube dysfunction, which can result in possible fluid buildup in the middle ear and infections. Ear tube placement will help facilitate restoring hearing and draining the fluid from the middle ear (AAO, 2017). Speech and language delays are also common in the cleft lip and/or palate because of structural changes. The child oftentimes will be unable to clearly pronounce and form certain words. Speech therapy will be paramount after surgical repair to correct these delays in communication. These interventions can be a social issue rather than only a medical issue in the Asian American population, because of the potential shared or deferred-type decision-making cultural belief, as well as their belief in the preservation of harmony (McLaughlin & Braun, 1998).

Orofacial cleft children can potentially have dental problems because of missing bone in the gum line (alveolar ridge). Certain teeth can never come through, or they can come in crooked and misaligned. There are times where a child may have extra teeth. Children with associated dental problems will need to be followed up closely by a dentist and an orthodontist who are specialized in clefts, so coordinated treatment can begin in a timely fashion (Goswami et al., 2016). It will be especially important for providers working with the Asian American culture to not make any assumptions regarding dental care and what is understood. Asian Americans do not believe in direct eye contact or direct questioning and candidness. It is considered rude and invasive of one's privacy (Cheng, 1990). Providers will be faced with Asian Americans nodding their heads and having little verbalization spontaneously out of respect for authority, and not as an indication of the agreement with the treatment plan (Cheng, 1990, p. 299). Providers should provide and communicate concise information regarding dentists and orthodontists who specialize in clefts, potential costs, and resources available to help them obtain the needed dental care for their child.

The social stigma attached to physical appearance for some, as well as the psychological issues, many of these orofacial cleft children face poor self-esteem, and a poor self-image, are a unique challenge for not only the parents, but for the health care providers (CDC, 2017; Richman, McCoy, Conrad, & Napoulos, 2012). Many of these children have social adjustment and social expression problems (Sinno et al., 2012; Sousa, Devare, & Ghanshani, 2009). In the Asian American culture, counseling the parent and providing support may be challenging due to the belief in male dominance and the patriarchal influence in the family, with the father responsible for the final decision. The Asian American highly values and takes pride in "saving face," or it will bring great shame not only on the child, but immediate and extended family, and community as well. Therefore, providers need to be cognizant to this when making recommendations regarding management and care for their child. Care needs to be obtainable, relevant, and culturally sensitive so as to not set the individual and families up for failure.

TREATMENT OF CLEFT LIP AND CLEFT PALATE

Appropriate treatment of a cleft lip and cleft palate requires a multidisciplinary team approach to provide the comprehensive and culturally aware care needed. The multidisciplinary team members should include plastic surgery, dentistry, speech pathologist/therapist, nursing, audiology, genetic counselors, team coordinator, psychologist/therapist, and oftentimes orthodontics, and a maxillofacial surgeon (Burg et al., 2016; Cassell et al., 2014; CDC, 2017). Not every health care organization has a craniofacial team and cleft center, so it is of the utmost importance to find a center that is able to provide the multiple surgical procedures and follow-up that will be necessary. Allam et al. (2014) indicated that there is evidence of increased positive outcomes for these children when treated at a cleft center. The logistics and cost associated with traveling to a craniofacial center can be a realistic barrier to care for the Asian American family with an infant or child with a cleft (Cassell et al., 2014). Consideration needs to be given to the cultural diversity of this population; care plans, communication styles, support systems, and medical services need to be adapted and developed to meet the needs of this population.

The management and treatments needed will depend on how severe the clefts are, associated birth defects and/or syndromes, the age of the infant/child, and other medical needs (Sinno et al., 2012). Many studies have debated the timing of surgical repair of a cleft lip and cleft palate. Arguments associated against early surgical intervention are due to the concern regarding facial growth, whereas others have argued against late repair due to the speech problems (Burg et al., 2016). Repair of a cleft lip can be done when an infant is 10–12 weeks of age, but typically is completed by the first year of life. A cleft palate can require a staged repair, and may also require multiple revisions through adulthood. Typical repair is done between ages 9 and 12 months, but the initial repair should be completed by 18 months of age or earlier (American Society of Plastic Surgeons, 2019; CDC, 2017). According to Burg et al. (2016), earlier treatments with nasoalveolar molding, external taping, and gingivoperiosteoplasty can minimize the needed surgical procedures

(Burg et al., 2016, p. 12). When a child has an associated alveolar cleft with a cleft palate, bone from the hip is needed to fill the space in the gum line so that teeth (permanent) can be supported and the jaw stabilized. Bone grafting takes place commonly after age 7 years (CLAPA, 2019; Weissler et al., 2016). The complexity and timing of these medical interventions can be challenging for the parent, family, and provider.

CONCLUSION

In a country with the diversity as seen in the United States, providing care for individuals from other cultures creates opportunities and challenges to health care providers and health care organizations. A condition like orofacial clefts with the complexity of the condition, the complexity of the medical interventions, and the cultural intricacies of the Asian culture, creates a state that requires a significant knowledge and understanding by the health care providers. In addition, there is a need to improve access to craniofacial centers and increase the availability of cleft care for the Asian American and other ethnicities. Increasing access, and ensuring providers are familiar with the expressions, beliefs, communication styles, and assumptions of this culture, will enable the health care system to provide coordinated, culturally sensitive, and quality care.

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